

Lymphoedema prevalence in the West Midlands region

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Key words

Breast cancer, gender, lymphoedema, prevalence, praecox

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Lymphoedema is a chronic long-term condition, resulting in oedema formation, either as a singular or combined presentation (Lymphoedema Support Network, 2010). It has been stated that instances of lymphoedema have been underestimated (Moffatt et al, 2003), which led to the creation of a report, highlighted here, in an attempt to gain a more accurate insight into prevalence levels in the West Midlands region.

It is estimated that the overall prevalence of lymphoedema ranges from 0.13%–2% (Moffatt et al, 2003), with a worldwide estimate of 120 million (Lymphoedema Framework, 2012). Secondary lymphoedema is estimated to affect 100,000 within the UK (Moffatt et al, 2003), with the estimates of primary lymphoedema ranging from 1:6 000–1:33 000 (Baskerville, 1989; Rockson, 2001). The ratio figures for primary lymphoedema give a potential estimate at between 1:1 888–1:10 383, based on a population figure of 62.3 million within the United Kingdom, according to the Office for National Statistics (2011a).

Abstract

A report was produced, focusing on the overall prevalence of lymphoedema in the West Midlands region with further analysis relating to diagnosis, caseload gender, average caseload, and staffing levels. The information was provided by 43% of British Lymphology Society members in the West Midlands between May and June 2012. However, the figures were affected by the lack of detailed information provided by services and the inclusion of patient discharge figures. The main findings indicated that the prevalence figure extrapolated was 0.153%, with primary lymphoedema accounting for 6% of caseload figures, compared to secondary lymphoedema accounting for 94%. The main diagnosis of primary lymphoedema was praecox, compared to secondary lymphoedema diagnosis being cancer related. Caseloads comprised an average of 574 people, with 94% being female. Staffing levels were compared to the proposed figures from the Wales lymphoedema strategy (Welsh Assembly Government, 2010), which indicated an understaffing of 22.7%. In conclusion, the report offers further insight into the prevalence figures within the West Midlands, and can be used as a benchmark for future research. However, this report has limitations that affect the accuracy of the figures produced. It has been recommended that an annual report, wider participation, increased detail, and inclusion of patient discharge figures would improve the accuracy and impact of a future report.

Method

The report was proposed by the West Midlands regional representative of the British Lymphoedema Society (BLS), aimed at collecting data from BLS members in the region to produce a prevalence figure of lymphoedema. This included data on overall lymphoedema prevalence with further analysis in the areas of primary/secondary lymphoedema, average caseload, and gender. A cross-sectional study was adopted through the use of an emailed questionnaire, which was to be completed over a 2-month period between May–June 2012. The data were intended to provide a baseline of information, which could be utilised as a benchmark for future reports.

Results

Total population and prevalence

The current population for those services participating within the survey outlined in this article stands at 2 075 400 (Office for National Statistics, 2011b). Based on the population figures, it is estimated that the number of lymphoedema cases would number between 2 698 (0.13%) to 41 508

(2%). Caseload figures provided between May–June 2012 stood at 3 186, representing a prevalence percentage of 0.153% (Figure 1). However, this figure could be higher if those patients who were discharged were included, for example, those who are self-managing their ongoing lymphoedema condition.

Primary lymphoedema prevalence

Only 50% of those services in the West Midlands who agreed to participate in the study were able to provide details on the incidence of primary lymphoedema within their caseload. This led to the estimate of primary lymphoedema being based on a patient figure of 57, and an area population of 1 200 900. This led to a primary lymphoedema estimate ratio figure of 1:21 000 within the West Midlands between May–June 2012 (Figure 2). Again, this figure would be higher if those who were discharged had been included.

Primary/secondary lymphoedema caseload percentage

The figures provided from those services participating within the survey between May and June 2012 indicated that primary

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lymphoedema accounted for 6% of the caseload, with secondary lymphoedema accounting for the remaining 94%.

Average caseload and gender percentages

It has been estimated that the average caseload per service is 574 patients, based on the total caseload figure of 3 186 within the West Midlands region between May-June 2012. A total of 83% of lymphoedema services provided information on gender, which indicated that 78% were female compared to 22% males.

Primary and secondary lymphoedema diagnosis

Only 33% of the participating lymphoedema services were able to provide details on the specific diagnosis of primary lymphoedema, which represents a potential patient population of 643 500. Figure 3 records these findings and shows that the main diagnosis within primary lymphoedema is praecox, accounting for 5% of the combined caseload in the West Midlands region. Once again, this figure does not include those patients who had been discharged.

Based on the information provided, there are three main causes that lead to the development of secondary lymphoedema. These have been identified as cancer (45%), lymphovenous disease (25%), and immobility/dependency (13%) (Figure 4).

Staff-to-patient ratio

The current caseload population for the 43% of lymphoedema services participating within the report stands at 3 186. If this figure is compared to the optimum staff-to-patient ratio recommended within the Strategy for Lymphoedema in Wales (Welsh Assembly Government, 2010), there should be 21.2 full-time equivalent (FTE) therapists. However, there are currently only 16.4 FTE therapists in place, which represents a 22.7% understaffing of lymphoedema services.

Discussion

The estimated prevalence of lymphoedema within the West Midlands region stands at 0.153%. However, not all services in this region participated in the compilation of the report, and some of those who did participate were not able to provide information pertaining to all of the sections. It is also acknowledged that the report does not include those who have been discharged from lymphoedema services, and that

Figure 1. Prevalence of lymphoedema both locally (West Midlands) and nationally.

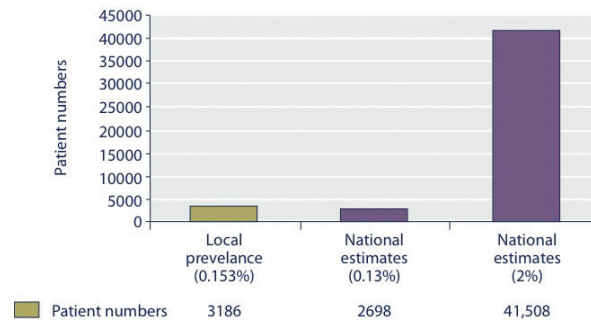
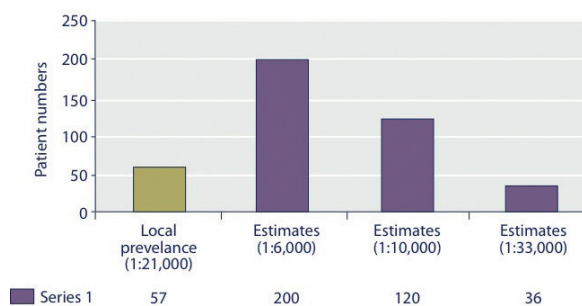


Figure 2. Prevalence of primary lymphoedema in the West Midlands compared with estimates.



factoring in those cases would significantly increase the prevalence figure.

The main diagnosis of primary lymphoedema relates to praecox, and the main diagnosis of secondary lymphoedema relates to cancer. If more detailed data were available, further analysis may have been possible, for example, examining whether the majority of cancer diagnosis relates to females and whether it is predominantly breast cancer-related.

It has been noted that there is a higher percentage of females affected by lymphoedema compared to males within the total caseload. However, without information on age and gender, the ability to extrapolate potential reasons for this occurrence is limited. Were more detailed data to come available, it would be possible to analyse whether the majority of cases fall within the 60–80 years age range, for example, and whether they represent the caseload diagnosis of lymphovenous disease/immobility.

The current staff-to-patient ratio figures proposed within the Strategy for Lymphoedema in Wales (Welsh Assembly Government, 2010), indicates that there is an understaffing of 22.7%. There could be multiple reasons for this, such as lack of policy recognition, current austerity

measures introduced by the coalition government, and a lack of staff-to-patient ratio guidelines.

Limitations

This study had a number of limitations that prevented it from achieving a higher level of detail and accuracy. The limitations relate to the level of participation by BLS members with only 43% of services participating in this survey. Out of 43% of those services, 33% were able to provide detailed diagnosis figures, 50% were able to give overall primary/lymphoedema figures, with 83% providing male/female figures. It has also been acknowledged within the report that the figures produced do not include patient discharge figures. Although the accuracy of the report is compromised by these limitations it, nevertheless, offers insight and clarity, which may not have otherwise been identified without the report's commissioning.

Conclusion

The report has provided an insight into the prevalence of lymphoedema within the West Midlands region between May and June 2012, which differs from national estimates. The main diagnosis of primary and secondary lymphoedema has been identified, but is only based on information provided by 14%

Figure 3. Specific diagnoses of people with primary lymphoedema.

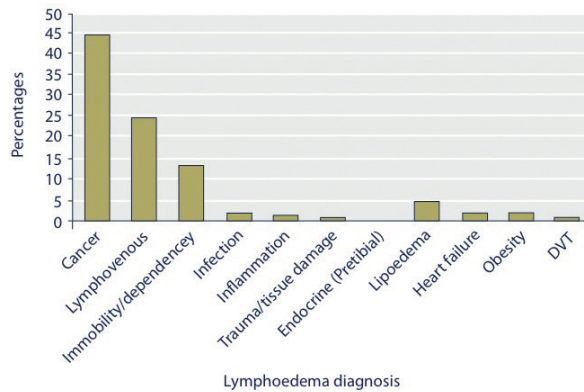
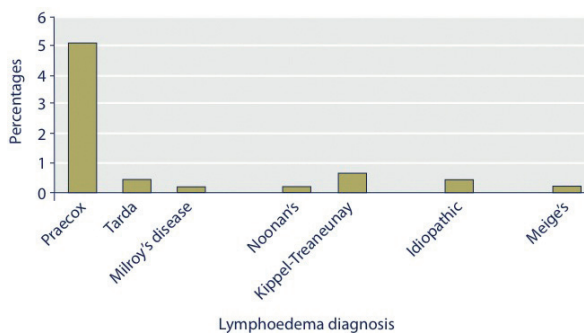


Figure 4. Specific diagnoses of people with secondary lymphoedema.



of those who participated. These figures and subsequent interpretation are subject to change if increased involvement within any future report does occur.

Despite these limitations, the report does indicate that the current caseloads have a higher proportion of female to male patients, with the reason of this occurrence unknown. It has also been noted that the current staffing numbers based on the proposed optimum levels is insufficient for the management of the current patient population.

The limitations have been discussed throughout the report and could be resolved through the stated recommendations. However, this will require all parties to have the necessary support and processes in place to ensure that any future report will address the matters raised.

Recommendations

Wider participation

It would be beneficial for all lymphoedema services in the region to participate in any future report, as this would increase the accuracy of the figures produced. The reasons for non-participation would need to be identified through the use of suitable communication channels. This may involve

individual or group meetings with those services that chose not to participate, to explore the reasons underpinning their nonparticipation while identifying strategies to remove any barriers in the future. Other communication methods could be utilised in the form of telephone calls, teleconferences, and written requests.

Increased detail

The ability to use detailed information regarding lymphoedema diagnosis and the age of those affected would have enabled the report to identify trends and create a more accurate benchmark. However, variations in clerical, IT, and other resources, present difficulties in collating this information. This matter could be discussed further in BLS meetings to determine a potential solution to these problems. One possible solution could be the use of an agreed *pro-forma* in either Word or Excel format, which could be utilised by services to input/update data over a 12-month period. Another possible solution could be reaching an agreement to roll out a standardised software/database across all services. However, this option does incur costs that health services may not wish, or be able, to commit to.

Annual report

The ability to repeat the report would assist in establishing the incidence of lymphoedema, compared to the benchmark figures produced within the current report. An agreement from all participating services within the report to submit similar or enhanced levels of information would be required in order to achieve this.

Participation could be encouraged through the use of all available communication channels, such as BLS members meetings and the exchanging of email correspondence. The aim, purpose, and benefit of participation within the report could then be communicated in this way. Additionally, a dialogue would be created to discuss matters that may expand or prevent the effective completion of a future report.

Patient discharge inclusion

It would prove beneficial to include the people who have received a diagnosis of lymphoedema, but have been discharged. The inclusion of these figures would increase the accuracy of the report and may lead to further recommendations related to this area.

As previously discussed within the recommendation section of this article, BLS members meetings could be utilised to discuss how best to collate data. Other possible solutions could be the adoption of a standardised database or electronic *pro-forma* to better encourage all clinicians to participate in collating more accurate and useful data.

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